

Complete Title:

Dementia in the Bangladeshi diaspora in England: A qualitative study of the myths and stigmas about dementia

Short Title:

Dementia in the family: The Myths and the Stigmas

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Abstract:

Rationale, aims, and objectives: Although Bangladeshis are three times more likely to be carers than White British, Bangladeshi family carers are the most deprived, neglected, and effectively a hidden group in the UK.¹ There is a paucity of research within the Bangladeshi community that is capable of explaining and predicting what the experiences and concerns of Bangladeshi family carers providing care for their relatives with dementia. The purpose of this study is to explore the perspectives of Bangladeshi family carers' knowledge and day-to-day experiences living in England.

Methods: Qualitative study involving semi-structured face-to-face interviews with six Bangladeshi family carers living in London and Portsmouth. Interviews were recorded with the consent and transcribed verbatim. Data was managed by using NVivo software and thematic analysis was performed.

Results: This paper explores that most carers have a lack of knowledge and awareness of the symptoms of dementia. The results of this study are in contrast to previous studies, where South Asian carers perceived dementia as being possessed by evil spirits or God's

punishment for previous life's sins, this study reveals Bangladeshi family carers believed dementia was a medical condition. Unlike earlier South Asian studies, however, all family carers in this study also believed there was no stigma attached to dementia.

Conclusions: Further research is warranted to investigate the religious beliefs, familism, and interpersonal motives as theoretical perspectives to explain how Bangladeshi family carers negotiate and construct their caregiving roles for their relatives with dementia.

Keywords: dementia, family carer, carer burden, stigma, knowledge, awareness, ethnicity, Bangladeshi

Introduction

Bangladeshi diaspora is one of the fastest growing immigrant populations among all major ethnic groups in the United Kingdom (UK) as well as around the world.² The earliest records of the Bangladeshi diaspora community first emerged in the UK as early as in the 17th century, and the majority of them arrived as lascars, or merchant seamen.³ Later, Bangladeshi immigrants began to arrive in large numbers for the first time in the 1970s following the founding of Bangladesh in 1971. Though most of these migrants initially came from three regions of Bangladesh – Sylhet, Chittagong and Noakhali – migrants from Sylhet (in the northeast of Bangladesh) came to dominate the migration flow to the UK, and today more than 90 per cent of Bangladeshi immigrants in the UK have come from Sylhet.^{4,5} Bangladeshi immigrants are mostly concentrated in the inner London in boroughs such as Tower Hamlets, Newham, Camden and Southwark. There are also large numbers of Bangladeshi immigrants living in Birmingham, Manchester, Oldham, Luton, Bradford, Cardiff and Portsmouth.

Black, Asian and Minority Ethnic (BAME) is the terminology normally used in the UK to describe people of non-white descent.⁶ The BAME group refers to non-White communities whose roots are mainly in South Asia, Africa, the Caribbean, China, Turkey, and Ireland. It is possible that the South Asian population, including Bangladeshi, can sometimes be misrepresented under the constructed designation of BAME. Furthermore, the largest mass migration from Pakistan to Britain was recorded in the early 1960s,⁷ at a time when Bangladesh was a provincial state of Pakistan, known as East Pakistan. Hence, even though the last decades have shown that Bangladeshis are a fast-growing ethnic minority, these figures may underestimate the actual number of Bangladeshi immigrants living in Britain to date. Bangladeshis were generally combined into the category 'Pakistani' for much of the period until 16 December 1971, when Bangladesh won its independence from Pakistan and appeared on the world map. Therefore, it has been argued that the Bangladeshis represent a

hidden community.⁸ Despite increasing numbers, the immigrant Bangladeshi community often represents the lowest education rates and disproportionately high rates of unemployment, overcrowding, and poorer socio-economic and health conditions among the overall population of Britain.^{9,10}

Ageing, dementia and culture

Whilst ageing is an inevitable and irreversible process, it is a complicated concept with biological, psychological, and sociological consequences. There is a substantive literature on how different cultures perceive old age and dementia.^{11,12} With cultural differences apparent, one generation's experience of old age and dementia can be different from succeeding generations.¹³ Most cultures engender, in its own communities, ideas about what successful ageing means, of the kind of respect due to an older member of society, and of the types of relationships that should exist between an elderly parent and his or her child. Age is defined by society and as such, the definition of age may be varied across cultures.¹⁴ Culture differ in their attitudes towards their elderly members and the expectations of older people as well as status attributed to old age and this includes issues such as a person's lifestyle expectations and the roles and responsibilities, they anticipate for themselves. In some societies, old age is defined by functional terms, based on one's ability to perform certain activities, as well as increasing age is accompanied by increasing prestige. For example, in Bangladesh, the oldest members of the family may be treated with reverence and respect, as well as hold a prominent position within the family and society based on their cultural values. Much prestige can be afforded to the person who is qualified to be called "old man" in Bangladesh. However, such prestige and respect can be challenged when older Bangladeshi people live in a youth and work oriented society like Britain. Nonetheless, for many UK Bangladeshi elderly migrants with dementia and their informal carers, it can be difficult to adapt cultural expectations, and this can create individual and family stress.

Dementia is an overall term used to describe a syndrome due to a disease of the brain, usually of a chronic or progressive nature that exist when brain cells die and stop working properly.¹⁵ The symptoms are likely to include memory loss, confusion, inappropriate behaviour, getting lost, problems with communication or difficulty finding the right words, faulty reasoning, sleep disturbance, hallucination, fainting, and agitation.^{16,17} Dementia also leads to a reduction in a person's abilities and skills in carrying out routine activities such as washing, dressing and cooking. Additionally, age is the most significant known risk factor for dementia. Dementia affects men and women in all social groups and therefore, the prevalence of dementia increases exponentially with age.¹⁸ However, despite increasing numbers of older people no specific research has been carried out to understand the dementia experience among the Bangladeshi community in England. Even there are no exact numbers concerning the

prevalence of dementia within the Bangladeshi community. The number of BAME patients with dementia in the UK is estimated to be 25, 000 and this number is predicted to rise to 160, 000 by 2051.¹⁹ Nevertheless, there is no word in Bangladeshi or in any other South Asian languages that has exactly the same connotations as the word 'dementia'. Although this can create potential barriers for a discussion about dementia, it is instead sometime explained by using derogatory words, for example, 'madness', 'forgetfulness' or 'losing memory' in old age.²⁰

Purpose

This qualitative study aimed to explore the British Bangladeshi family carers' knowledge and day-to-day experiences of dementia. The data collection of this study aimed to conduct semi-structured audio-taped qualitative interviews with Bangladeshi family carers who play an important role in supporting their older relatives living with dementia.

Methods

As there is currently no dementia research among the Bangladeshi community in the UK, qualitative research was utilised. Qualitative research is particularly useful for exploratory research where little previous research has yet been undertaken to capture the meaningful experiences and life values, explore the attitudes, and perceptions of persons with dementia and their family carers.²¹ In addition, qualitative research starts from the assumption that one can obtain a profound understanding about people and their worlds from ordinary conversations and observations. Its empiricism is grounded in the everyday data of experience.²² Qualitative research, despite linguistic and cultural differences, can elicit grief, joy, sadness, anger, and other strong emotions from the gestures and talk of individuals. Therefore, a qualitative approach was the most suitable for this investigation because it focused on people's feelings, meanings, experiences, and perceptions; it was also essential to conduct the study within three primary ethical principles: 'beneficence', 'respect for human dignity', and 'justice'.²³ The overriding concern was to protect those involved from harm and distress.

Sampling strategy

Conducting this study among the Bangladeshi community presented significant challenges for recruiting potential participants. The Bangladeshi community is often reported as a hidden population in the UK,²⁴ whereas Bangladeshi family carers are the most deprived and concealed group among them.²⁵ Therefore, purposive and snowball sampling were used to collect data from the family carers of people with dementia. A combination of purposive sampling (selection based on predefined inclusion and exclusion criteria) plus snowball sampling (where those recruited suggested others who might be interested as well as

potentially eligible to take part in the study) were particularly useful for dealing with the underprivileged, geographically dispersed and hard-to-reach Bangladeshi community in Portsmouth and London, where no usable sampling frame exists.²⁶

Given that the participants were harder to reach than expected, it was originally planned to recruit approximately 20 participants from Bangladeshi family carers, caring for Bangladeshi older people with dementia. As a result, contacts were made with 20 potential participants; the first author contacted family carers directly or via a male family member or a guardian of a female family carer. A total of 12 family carers expressed an interest in the research. However, the number that finally agreed to participate was lower than had been anticipated. A sample of five family carers refused to attend the interviews due to the gender differences between them and the author. Two potential participants were referred through snowball sampling procedures; in both cases, the interviewed person provided the referral facilitated in communicating the potential participants. However, one participant met the inclusion criteria and other was excluded from the study. The research thus proceeded with six Bangladeshi family carers, living either in Portsmouth and London. Half of the participants were female, and half were male.

Inclusion criteria for Semi-structured interviews

Following approval from the research ethics committee, participants were selected according to the following inclusion criteria:

1. Bangladeshi origin or British born Bangladeshi family carers (minimum 18 years, with no upper age limit) caring for, or have cared for, Bangladeshi people with dementia
2. The participant has been a carer for at least six months for a family member who was diagnosed with dementia
3. A family carer was previously a carer for someone with dementia no longer than two years ago
4. Able to provide written informed consent
5. Able to take part in a semi-structured interview conducted either in Bengali, English or a combination of both

Data collection

Informed consent

Prior to recruitment, full ethics approval was obtained from a local independent research ethics committee. Information sheets and consent forms were supplied to each of the potential participants who were interested in taking part in this study. Participants were asked to complete a consent form before the interview began, which also provided details of the study.

The consent forms outlined issues such as the purpose of the study, confidentiality, data storage and protection, how the results would be presented and the participants' right to withdraw. Each participant received a copy of the signed consent form; one copy of this consent form was placed in first author's file, which was stored in a locked cabinet in his university office.

Choice of venue

Each participant was given an opportunity to choose for the interview to take place in their home or at the first author's university premises. Three semi-structured interviews were conducted at the first author's University, either within the office of the author and University library, for which he sought permission to use a secure and private interview room. The remaining three interviews were conducted at the participants' own homes. Where interviews conducted in family carers' own homes, it was made clear that perhaps a relative or a friend would need to look after the person they cared for. As a result, three carers' three closed family members, such as a wife, a sister, and a son respectively looked after the people with dementia whilst the carers were being interviewed.

Semi-structured interviews

Data were collected using in-depth semi-structured qualitative interviews. The semi-structured interview as a data collection method is ideally suited to obtain relevant stories with meaning, distinctiveness, and context associated with the participant's background. Semi-structured qualitative interviews typically involve a context in which the interviewer has a series of topics to guide the interview process, but the sequence of topics is not set, and the participant is encouraged to introduce new topics, deviate, and provide a context relevant to the purpose of the research study. Informed by current literature, an interview schedule was developed to guide the process. The interview schedule provided flexibility and allowed researcher to probe and expand interesting ideas arising from the stories the participant wished to share during the interview. The topics and questions in the interview schedule provided a frame of reference, rather than an inflexible structured process.²⁷ Initial topics encompassed the experience and understanding of dementia; when and how the family carers realized that something was wrong with their relatives with dementia; how and why the family carers sought help for dementia problem; the carer's attitudes towards dementia and the person they cared for; was there any stigma attached to dementia; the nature of stigma within the family and community; were they stigmatized by looking after their relatives with dementia? The topic guide was designed to follow the family carers' own concerns. Therefore, every effort was made to keep the conversation flow smoothly. The recorded interviews lasted from some 60 to 90 minutes approximately, depending on what participants wanted to share. Five interviews were conducted in English and one in Bengali and transcribed verbatim. The first author

translated and transcribed the Bengali interview recording and checked the interview transcription against the tape recorder. In addition, a local trained and experienced bilingual research assistant checked the Bengali interview transcription against the tape recorder for double accuracy.

Data analysis

All interview transcripts were subsequently entered into the QSR NVivo 10 data management program,²⁸ a comprehensive process of data coding and theme identification was undertaken. A thematic analysis was chosen as the preferred method to analyse the findings from one-to-one semi-structured interviews. Braun & Clarke's²⁹ thematic analysis was used which followed six clear and detailed key stages, such as (1) familiarisation with the data, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, (6) producing the report. The authors repeatedly read the transcripts to identify a number of recurring concepts, generating initial codes which developed until primary recurrent themes emerged by using the adaptation of Braun and Clarke's²⁹ six steps. Thematic analysis was a recursive, rather than linear, process where authors moved back and forth as needed throughout the six steps. Thematic analysis delivered an efficient component to data analysis that allowed authors to extensively understand the phenomena under investigation. Therefore, thematic analysis allowed the authors to realise what phenomena prevailed in situation where Bangladeshi family carers provided care for people with dementia and a close examination of why this was the case.

Validity of the study

In order to establish trustworthiness and credibility for this study, the authors leveraged two critical techniques to evaluate the study: triangulation and member checking. Authors used source or setting triangulation (i.e., Bangladeshi family carers were interviewed from diverse backgrounds; these included male and female holding different professions, of different ages, and in two different settings – London and Portsmouth). Secondly, the authors employed analysis triangulation using NVivo, a qualitative software, as well as pen-and-paper data analysis. NVivo was used as an audit trail; as a result, the qualitative analysis became very transparent and trustworthy. Also, the authors followed Braun and Clarke's²⁹ criteria for performing good thematic analysis by using a 15-point checklist to ensure that the thematic analysis processes were thorough, plausible, and of high quality. Lastly, the authors extensively utilized member checking. Member checking has been considered the most crucial technique for establishing credibility.³⁰ It is a participant validation technique to help improve the accuracy, credibility, and transferability of the research.³¹ Member checking was utilised once the transcripts had been generated from the interviews and examined thoroughly by the authors. The authors were aware that participants might be confused, distressed, or

embarrassed after reading their interview transcripts.³² However, participants were cautioned that the transcripts were written in their spoken languages, hence, any fragmented sentences or grammatical errors in their transcripts verified that the transcripts accurately conveyed their responses in the study.

Results

Family carers' age range was from 23 to 64 years, with a mean age of 44.16 years. All family carers lived with and reported providing care to a family member with dementia. Between them, two female family carers, a daughter and a wife provided care for their mother and husband, respectively. All males were non-spouse family carers, looking after their elderly parents with dementia. Out of six family carers, four were born in Bangladesh and two were born in England. Two carers worked full-time up to two months before their relatives had a diagnosis of dementia. One female carer never had a paid work. A male carer left his well-paid job completely and became a taxi driver. Driving a taxi fitted in around his caring role for his mother with dementia. Two other carers (one male and one female) having reduced their hours of work because of their heavy caring responsibilities. For one female carer, after leaving her job entirely, carer's benefit was only an important source of her independent income.

Emergent themes

The findings from the thematic analysis are presented in terms of two broad themes, relating to the family carers' experiences of dementia: early symptoms and diagnosis of dementia, and the myths and stigmas around dementia. These themes revealed Bangladeshi family caregiving experience in the journey through the development of knowledge and understanding of potential dementia symptoms, getting the diagnosis, and providing appropriate care.

Early symptoms and diagnosis of dementia

The early recognition of symptoms and diagnosis of dementia was vital for gaining knowledge as well as seeking help and support. However, the majority of family carers reported that it had taken a long period of time to familiarise themselves with the early symptoms of dementia. Eventually, all the family carers appeared to have recognised the premature symptoms of dementia that were initially perceived as unusual or inexplicable personality changes. However, not every family carer immediately sought help for their family member during this early stage of developing dementia. From the six family carers, two waited up to 10 years, three waited up to three years to seek help and learn about dementia as their family members displayed potential dementia symptoms. The minimum time spent to detect potential changes and symptoms of dementia was up to three months.

Between the two-family carers who took almost 10 years to detect the signs of dementia, the first family carer was previously looking after her father, and now currently her mother with dementia. Her father died from dementia, but he was never diagnosed. She acknowledged it was hard to pinpoint when her father first showed potential dementia symptoms as it was continuing for a long time until he died. On many occasions, she contacted her General Practitioner (GP), however, her Bangladeshi doctor repeatedly dismissed her concern for her father and suggested that it was nothing serious but only signs of getting old. The family carer mentioned that back in 2006, there was no awareness of dementia like we have today.

With my dad, I didn't realise. Because he had never been diagnosed with dementia. So, when we went to [our] GP, he said it was because of my father's old age. He didn't say anything about dementia. We didn't know what to do with him. We thought you know he's gone and became like a child. I became his mother. (Family Carer #2, 34 years)

However, she had a positive experience with her new GP for her mother's diagnosis of dementia in 2012. She expressed her resentment, as she did not know the cause of her father's death, however, she was relieved when her mother was diagnosed with dementia with the same symptoms her father had gone through without receiving any help. As her mother was diagnosed for dementia with the same symptoms, although at that time it was unknown, now she believes that her father died from dementia.

In a similar manner to Family Carer #2 above, Family Carer #3's husband's dementia symptoms were dismissed by the GP and they were unable to get a diagnosis. Family Carer #3 went on to say that her husband's symptoms were increasing day by day and after a few months he developed uncontrollable urinary incontinence. However, again, the doctor was reluctant to refer him for a dementia diagnosis. Instead, the doctor suggested that his symptoms were due to the natural causes of ageing.

After living with potential dementia symptoms for one year, he was having difficulties with urinating. Suddenly he began to urinate unexpectedly and unconsciously. [The] doctor said [that] men normally suffered from urinating in old age. (Family Carer #3, 64 years).

She did not discover that those symptoms could be possible signs of dementia until she met a dementia adviser from the **Alzheimer's Society** at an event. However, the remaining four family carers had a positive experience with dementia diagnosis and referrals, although not without similar difficulties in recognizing the potential symptoms of dementia.

The other male family carer had to wait for eight years, the second longest time, to get a diagnosis of his mother's dementia. Her admission to the hospital was not due to her early signs of dementia, but because of severe eczema on her legs. Her diagnosis of dementia

occurred only after her hospital admission for an acute medical problem. During her treatment for severe eczema, the doctor confirmed that she had dementia.

The early signs of dementia noticed were not solely restricted to memory problems, but physical or other kinds of cognitive and communicative problems, such as confusion or personality changes. The family carers' observations of unusual factors that could be potential early clues of dementia in their family members varied significantly. The family carers' statements confirmed their lack of knowledge of dementia and that their family member's admission to the hospital was not due to a memory loss, but for other major physical issues, and that the doctor subsequently ascertained that the underlying cause was dementia. Another participant explained that his mother was suffering from hallucinations and delusions, which led him to speak to his colleague for help. The family carer then immediately booked an appointment with a specialist, which resulted in the shortest possible period for a diagnosis of dementia identified in this research.

I noticed she talk[ed] to [the] television even [when the] TV [was] switched off. My sister was in Bangladesh, but she said that her daughter [was] calling to go to her house. So, I thought 'what's wrong?' After a chat with my colleague, I went to [the] doctor. [The] doctor did [a] CT scan and said [that] she was suffering from dementia. (Bereaved Family Carer, 52 years)

Each family carer experienced critical points with their caring journey for people with dementia, but their involvements were different in each case. Particularly, identifying the potential dementia symptoms and the process of diagnosis were crucial for a good beginning of their caring journey, rather than living with uncertainty. However, the process of diagnosis did not always begin speedily for each of these family carers after a visit to the GP or by consultation with a colleague or another immediate family member. The majority of the family carers acknowledged that they had no prior knowledge of dementia, with four out of six of them stating that they had never heard of dementia before their loved ones' diagnoses.

It seems from the findings that even after the diagnosis, the family carers did not automatically believe the doctors. Four family carers had no prior knowledge of dementia before their relatives' diagnosis and initially two of them did not accept it. Prior to the diagnosis, the family carers often experienced changes in their relatives' behaviour, including fluctuations in their ability to perform everyday activities, where symptoms became less steady and severe with time.

First, we did not believe the doctor when they said he [had] dementia. First, we thought, what is this disease dementia and why would he get dementia? But later we asked the doctor a lot of questions. Then the doctor explained to us what dementia is. (Family Carer #3, 64 years)

When the doctors confirmed the diagnosis of dementia, the family carers stated that they learned more about dementia themselves with the aid of the internet, as well as by reading books about dementia. One family carer explained how believing the doctor came as a relief. She was apprehensive and upset about her mother's strange behaviour and new symptoms, but she outlined how gaining more knowledge about the factors associated with dementia alleviated her turmoil and distress.

In two out of six cases, a diagnosis of dementia came as a shock to the family carers' immediate family as well as to the extended family members. This involved the family carer explaining the process of diagnosis and the term 'dementia' to other family members, which created additional pressure for them. One family carer became very anxious after learning that her husband had dementia. She and her children thought that dementia was a life-threatening contagious disease, and all the children suggested that she should go back to Bangladesh and stay there for the remainder of his life. The diagnosis of dementia made the participants learn a new way of providing care, which was continuous with their early family caring role. The family carers frankly discussed their caregiving experiences for their family members with dementia. Their caregiving experiences consisted of day-to-day caring responsibilities. In many respects, these seemed to be dominated by a daily round of caring responsibilities and related household tasks.

Myths and stigmas around dementia

In this current study, the myths of ageing and the misconceptions about the causes of dementia that accompanied Bangladeshi family carers' understanding of dementia were explored. Numerous physical and mental illnesses have been attributed by the family carers as possible causes of dementia, e.g., diabetes, depression, and stress. When asked, one of the family carers interviewed was reluctant to answer the question about the perceived causes of his mother's dementia.

Now it's a very difficult question. But [the] doctor said some parts of her brain cells have been damaged. [The] doctor also said that dementia... develops slowly. This is what happened to my mother. (Family Carer #1, 55 years)

Nonetheless, agreeing with the doctor's above explanation about his mother's dementia condition, Family Carer #1 went on to say that the symptoms of dementia were perceived differently in the Bangladeshi community and rejected the myths that dementia was a common part of ageing and loneliness. When asked, all the participants also strongly denied the myths and misconceptions that dementia was caused by *karma* (bad deeds) or because of a person's previous sins. Instead, one participant believed that her

392 husband's dementia was caused and given by Allah (God) as a mercy. According to her
393 religious faith, her husband's dementia, as well as any other health and illnesses, and every
394 success in life, was because of Allah.

395 *Allah gives disease, everything happens if Allah wishes. Every disease, every suffering*
396 *comes from Allah. Allah gives disease, Allah cures, we cannot say anything baba*
397 *(son). (Family Carer #3, 64 years)*

398 The findings of this current research have provided some evidence to suggest that
399 Bangladeshi family carers plus the wider Bangladeshi community harboured no stigmas and
400 resentments for dementia as well as for the people with dementia. Family carers did not
401 experience any noticeable stigma after the diagnosis of dementia or along their caring journey,
402 although family carers were merely incapable of providing religiously appropriate care for their
403 loved ones, such as same-sex care.

404 *No stigma, there is no stigma. Why should I feel embarrassed? My mother is suffering*
405 *from dementia and I am looking after her. I don't know is there any stigma related to*
406 *our relationship. (Family Carer #1, 55 years)*

407 Family carers also emphasised that dementia could happen to anyone. Extended family
408 members as well as the Bangladeshi community members were compassionate toward the
409 family carers and the care recipients. Most of the family carers (five out of six) used the word
410 'sympathise', when asked about the community members' attitude toward the family carers as
411 well as toward the persons with dementia. One family carer mentioned that her neighbour
412 sometimes cooked food for the person with dementia. Although the family carer assumed
413 there was no stigma within the Bangladeshi community, in the end they also stressed
414 uncertainty about the future generation's perception of the stigma of dementia.

415 Two out of six family carers interviewed described that the lack of knowledge about dementia
416 among the Bangladeshi community members led them to suspect that the person with
417 dementia was merely suffering from an unknown disease. Hence, they were sympathetic
418 toward the person with dementia. The family carer below stated that there was no stigma
419 before or after the diagnosis of both her parents' dementia, but she experienced persistent
420 fear before her mother's diagnosis of dementia. She did not have any prior knowledge about
421 dementia. However, she was not frightened anymore after the doctor confirmed her mother's
422 dementia condition.

423 *I don't feel ashamed. I have never spoken to anyone who showed any kind of stigma*
424 *toward me or my mom. The thing is people don't know what it is. They only know that*
425 *my mom is ill. So, they just give my mom sympathy, that's it. (Family Carer #2, 34*
426 *years)*

The other family carer said that some individuals were unable to notice any changes to her father with dementia by his exterior behaviour and appearance. Hence, they presumed that there was nothing wrong with him and doubted about the diagnosis of his dementia.

This research explores an important finding for the first time among the Bangladeshi community from the perspective of **myths and stigmas** around dementia and arranged marriage. It is worth mentioning again that the only family carer in this study sample who was 64 years old was a woman, a mother of eight children, three sons and five daughters. **The first author was** particularly interested to find out if there were any arranged marriage issues regarding their father's dementia problems in the family. She explained that her husband's diagnosis of dementia took place in the middle of her daughters' marriage ceremonies. Two daughters were married before his dementia diagnosis and the other three daughters' weddings happened after his dementia diagnosis. However, there were no stigmas associated with their father's condition of dementia among the newlyweds' families.

Discussion

This is the first study to explore knowledge and experiences of dementia among the Bangladeshi family carers of people with dementia in England. The main findings from the interviews reveal that the majority of family carers have a lack of knowledge and awareness of the symptoms of dementia. A lack of knowledge seems to be a common issue across the previous studies and symptoms of dementia are perceived differently within **the** broader BAME communities.¹⁹ However, the research discovered a shift in the conceptualisation of dementia among the Bangladeshi family carers against the conventional concept of memory loss, with memory loss being consistently conceived as an outcome of the ageing processes in the previous studies conducted among BAME groups. Even though the knowledge and understanding about dementia is very low and inconsistent in previous studies, the presentation of dementia is unique to Bangladeshi family carers. Previous studies reported that memory loss was the first symptom of dementia that the South Asian could identify easily.¹⁹ However, most Bangladeshi family carers identified behavioural changes in their relatives prior to their conceptualisation of dementia, which, of course, always occurred with the help of their doctors. On the other hand, memory loss was perceived as a normal ageing process among the overall South Asians. Unlike other published research on South Asian communities,³³ no family carers in this study said that it was a normal ageing process; almost everyone believed dementia was a medical condition such as a brain disease and that anyone could suffer from it. Therefore, believing that dementia is a medical condition facilitated family carers to hand over their relatives with dementia to the control of health specialists.

Differences in beliefs about the causes of dementia among the South Asian family carers and family members were found in the past studies. Religious affiliation was greater within the South Asian communities and the participants reported that dementia was potentially caused by evil spirits or punishment for their previous life's sins.^{20,33,34} As a result, the family members placed a blame on the person with dementia for their strange and unforeseen circumstances.^{34,35} However, this study did not find a link between dementia and the perception of being punished of past sins or being possessed by bad spirits. These findings contradict previous studies on the way in which South Asian family carers perceived the causes of dementia. One possible explanation for this variation in beliefs is that, generally, Bangladeshi people trust their GP and hospital doctors and value their advice. Overall, Bangladeshi people perceive professionals like GPs and hospital doctors as experts on any health problem. They believe health professionals have the authority make any decision concerning the patients' well-being.³⁶ This research led to the conclusion that religion and culture has less negative influence on Bangladeshi family carers' understanding of dementia. Therefore, Bangladeshi family carers cannot be represented homogeneously with other South Asians or BAME communities.

Furthermore, previous research demonstrates variability in attitudes toward dementia and feelings of stigma and highlights the need for further research to understand the extent of stigma, among all stakeholders: people living with dementia, family carers and service providers for specific South Asian communities. On the other hand, it could be argued that a striking aspect of stigma about dementia is its vicinity. Earlier studies across the globe reported that various cultural and religious factors influenced the understanding of dementia and stigma in different countries and communities. Such as, Mackenzie²⁰ studied the causes of stigma among carers of Eastern Europeans (Poland and Ukraine) and South Asians (India and Pakistan) living in England. The study discovered the causes of stigma among South Asians were the combination of religious and the beliefs about bad spiritual influences were the causes of stigma, which were different from Eastern Europeans. Eastern European carers' stigma was deeply affected by their relatives' previous life trauma, such as, political persecution, slave labour, starvation, and other World War II atrocities were perceived causes of dementia. South Asian Muslim family carers hid the person with dementia from anyone other than family members. South Asian Muslim family carers also perceived that having a family member with dementia would invite condemnation upon their family. As a result, family carers were isolated from the friends and other family members within the community.

A similar concept of stigma was reported in other religions as well, such as the findings of Jutlla and Moreland,³⁷ Jolley et al.,³⁸ and Bowes and Wilkinson,³⁵ as Sikh and Hindu family members and the community members blamed the persons with dementia for their own

condition. Concealing the dementia symptoms frequently meant hiding the afflicted person due to possible consequences from family members as well as the community.³⁷ Three other studies seemed to produce contrary results;^{33,39,40} for example, Brijnath and Manderson's³⁹ study found stigma associated with incontinence or violence among the Hindu respondents, rather than other symptoms of dementia, and Mukadam et al.⁴⁰ found less stigma among the White Christians where McCleary et al.³³ did not find any stigma at all associated with dementia among the Hindus living in Canada. Unlike other studies, South Asian respondents in both McCleary et al.³³ and Mukadam et al.'s⁴⁰ studies did not conceal their relatives' symptoms of dementia from outsiders and enthusiastically shared their experiences with the researchers; while in the latter stigma about dementia and negatives experiences about health services were mentioned by Black and African carers only. Thus, notions of stigma permeate cultural and religious perceptions of dementia in South Asian populations at every stage, from recognition of memory problems, to diagnosis and beyond.

However, taking into account cultural, religious or other beliefs, the fear of stigma was not present at all in the six Bangladeshi family carers interviewed for this current study. Moreover, in contrast with previous studies,^{19,20,41} participants described that they never hid the signs and symptoms of dementia before or after their relatives' developed dementia. One possible explanation for this is the uniqueness of their religious and cultural identity. Bangladeshi family carers believe that their religion, Islam, is a complete way of life which is influenced by the concepts patterned in the Qur'an. It comprises of comprehensive and rational beliefs and rites, moral values and obligations. To have dementia is believed to be the will of Allah and anyone could suffer from it. This belief is congruent with Rassool and Rozario,^{42,43} who found that an illness was perceived as a gift to test their purity. However, Muslim people are not homogeneous around the world; rather, there is a widespread diversity of different denominations within the religion of Islam. Some Muslim countries are less religious than others, some practices and strictly follow the Qur'an and Hadiths (the sayings of the Prophet Muhammad, pbuh) and some do not. There are clear differences between South Asians and other BAME groups, denoted by class, caste, experiences and time of migration, and origin from urban or rural areas.⁴⁴ Nevertheless, Salway, Chowbey, and Clarke,⁴⁵ Ali, Kalra, and Sayyid,⁴⁶ and Aspinall and Chinouya⁴⁷ argue that many of the ethnicity categories in the UK, including the term "South Asian", are too broad to be meaningful. They presume homogeneity within populations and neglect the variety of religious, ethnic, geographical or linguistic differences.

Limitations

This is the first study that explored the perspectives and experiences of the Bangladeshi family carers of relatives with dementia. As a first study, this research covered the areas that it intended to in a systematic way. However, there were a few limitations in this study and future research in the Bangladeshi community may look to expand on these areas. Sampling issues are a key problem in research involving Bangladeshi and other South Asian people with dementia and their family carers. Historically, South Asian immigrants have been a closed group in the UK.⁴⁸ Samples are limited by the relatively low response rates involved in this research. Unfortunately, due to the first author's gender and other suspicious issues (perhaps the author was a government secret agent), Bangladeshi people were the most difficult to reach and recruit for research participation. Due to the small quantity of participants obtained for this study, the sample may not be representative of all Bangladeshi family carers of people with dementia. Another limitation of this study is that perhaps the sample of participants was biased by self-selection. All the six family carers who took part in the study, strongly denied stigma attached to their perceptions and understanding of dementia. It is possible that family carers who were particularly stigmatised may not have taken part in the study; however, the family carers who had been in the caring role for a long period of time and who were regular attendees of the Bangladeshi family carer group meetings suggested that community members' attitudes toward them were non-stigmatised.

Conclusion

The current research provides an empirical contribution since there has been no other qualitative research examining the knowledge and understanding of dementia among the Bangladeshi community in England or elsewhere. The purpose of this study has been to examine in detail family carers' experiences of caring for their relatives with dementia. This study explores that most carers have a lack of awareness and knowledge of dementia. Family carers showed a deep sense of family obligation, religious beliefs, and interpersonal motives to provide care for their elderly family members with dementia at home. Family carers seemed to accept and take for granted, expectations to meet the significant caregiving roles. A shortage of culturally and religiously appropriate services for the needs of Muslim patients meant that Bangladeshi family carers were more likely to provide direct care themselves rather than receiving care from a service provider. Moving an elderly family member with dementia to a residential care home was seen as objectionable.

Another important, distinctive aspect of this current research that was inconsistent with previous research was that it explored myths and misconceptions about the stigma attached to dementia, which was not something Bangladeshi family caregivers had experienced along their caring journey. This research revealed that the Bangladeshi Muslim community showed

a very pragmatic attitude toward dementia, which was widely accepted as a medical condition and for which family carers openly sought health and social care support. Islam considers all diseases, including mental illnesses, as trials or tests from God and those types of suffering expiate sins. In a similar vein, not only will people with dementia be rewarded in the hereafter, but also their carers and family members who bear with them throughout the ordeal. Even the visitors of dementia patients will get their reward from Allah. The wider BAME communities may interpret dementia differently and may have preferred **approaches to help-seeking**, but in the Bangladeshi community, Islam plays a pivotal role in their understanding of dementia and access to services. In order to engage Bangladeshi immigrants with dementia services, their explicit religious identities cannot be ignored. The experience of dementia can be seen as one of the examples of the ability of their religious identity to overcome any stigma-related issues with illness, as well as to deal with caregiving consequences.

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